Genetic Counseling among Males: Results from the Hereditary Cancer Network Database

Background: Harmful mutations in the *BRCA1* and *BRCA2* genes substantially increase the risk of developing hereditary breast and ovarian cancer (HBOC) over the course of a lifetime.[1] Additionally, a *BRCA1* or *BRCA2* mutation increases the risk for pancreatic and prostate cancer. Variations in *MLH1*, *MSH2*, *MSH6*, *PMS2* or *EPCAM* genes are associated with Lynch syndrome (LS). LS is an inherited disorder that increases the risk for colorectal, endometrial, ovarian and other cancers. Genetic counseling with a board certified and/or board eligible genetics provider is the recommended first step for anyone with a personal history or strong family history of these cancers. The individual may then be referred for genetic testing as appropriate. Early identification of HBOC and LS can help reduce the impact of cancer and save the lives of family members who may also be at risk.

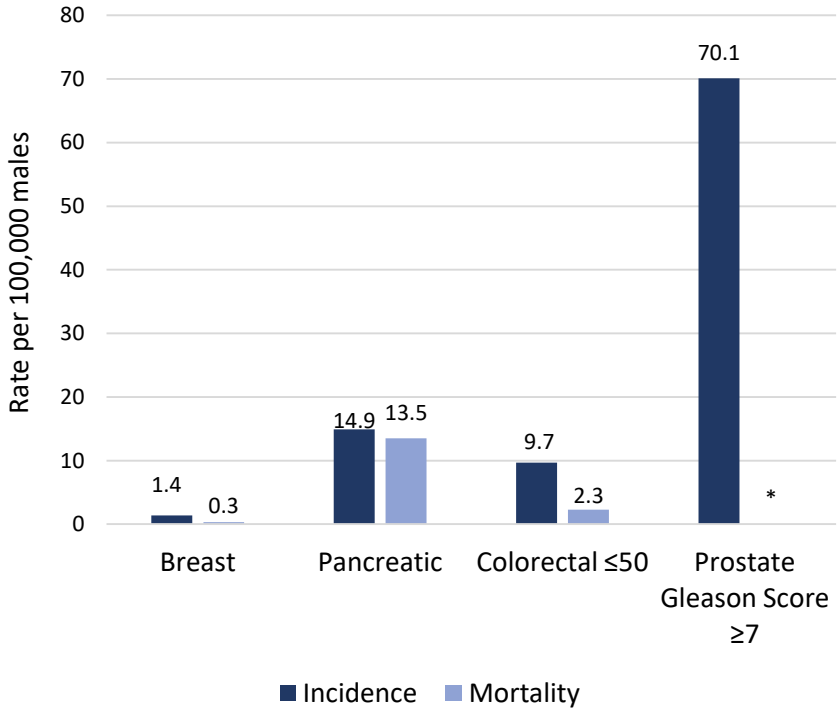
The National Comprehensive Cancer Network (NCCN) recommends that all males with breast cancer be referred for genetic counseling[2]. Additionally, males should be referred to genetic counseling if they have a personal history of prostate cancer with a Gleason score ≥7, if they are diagnosed with colorectal cancer at age 50 or younger, or if they have no personal history but have a significant family history of these cancers.

Methods: The Hereditary Cancer Network (HCN) Database started collecting non-identifiable information on patients seeking counseling for HBOC in 2008 and for LS starting in 2015. Eighteen clinics have contributed information to this database. This database only contains information on patients who present at a clinic participating in the HCN and therefore may not be representative of all genetic counseling performed in the state. A total of 29,363 patients who sought genetic counseling at the participating clinics between 2008 and 2017 with 2,374 being males. Frequencies were reported for various characteristics and χ^2 tests were performed to assess for differences amongst gender as well as differences between White and Black males. Incidence and mortality rates were provided by the Michigan Cancer Surveillance Program (MCSP).

Cancer Incidence and Mortality in Males

- According to the NCCN guidelines, all males with a personal history of breast cancer should be referred to genetic counseling.
    - In Michigan between 2012 and 2016, the incidence of breast cancer in males was 1.4 per 100,000 males.
- All males with a personal history of prostate cancer with a Gleason score of 7 or greater should be referred to genetic counseling.
    - In Michigan, the incidence of prostate cancer with a Gleason score of 7 or greater was 70.1 per 100,000 males.
- All people with colorectal cancer diagnosed at age 50 or younger should be referred to genetic counseling.
    - In Michigan, the incidence of young colorectal cancer in males was 9.7 per 100,000 males.

Incidence and Mortality Rates for Specific Cancers Associated with Possible Hereditable Cancers among Males from the Michigan Cancer Surveillance Program, 2012-2016



*Gleason Score is not available in Mortality Data Files

Data Sources: Michigan Department of Health and Human Services (MDHHS), MCSP, 2012-2016

MDHHS Vital Records Mortality Files, 2012-2016

Demographics by Sex

- A total of 26,989 females and 2,374 males are in the HCN database.
- A statistically significant difference exists between race and sex with 7.8% of females and 4.7% of males reporting their race as Black.
- A significantly larger percentage of males reported having Ashkenazi Jewish heritage (6.8%) compared to females (4.8%).
- A statistically significant difference exists between insurance provider and sex with 15.5% of females and 20.1% of males reporting having Medicare.
- A statistically significant difference exists between age at initial visit and sex with 48.6% of females and 40.1% of males being age 50 or younger.

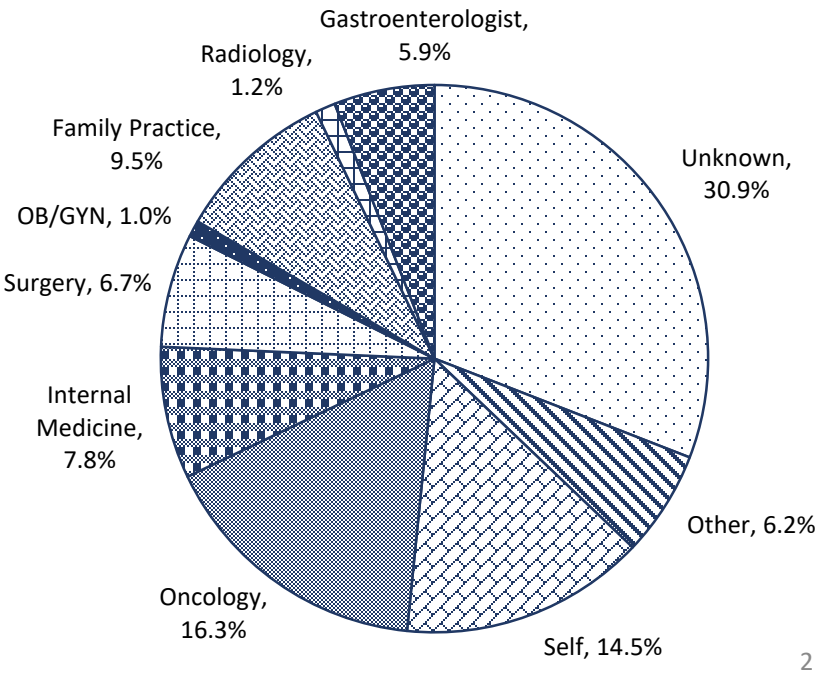
Demographics of the HCN Database, 2008-2017

	Females N (%)	Males N (%)
Race		
Black	2,106 (7.8)	111 (4.7)
Other	2,757 (10.2)	191 (8.1)
White	22,126 (82.0)	2,072 (87.3)
Ashkenazi Jewish Heritage	1,119 (4.8)	138 (6.8)
Insurance Provider		
Medicaid	1,566 (5.8)	88 (3.7)
Medicare	4,191 (15.5)	265 (20.1)
Uninsured	191 (0.7)	15 (0.6)
Private	20,767 (76.9)	1,768 (74.5)
Age at Initial Genetic Counseling Visit		
50 or Younger	13,124 (48.6)	950 (40.1)
Older than 50	13,865 (51.4)	1,424 (60.0)

Referring Provider Type among Males

- A statistically significant difference exists between referring provider and sex, with women being referred more often by a surgeon (25.2% versus 6.7%) and an OB/GYN (13.8% versus 1.0%) (data not shown).
- Among males, 30.9% did not report a referring provider.
- Among males, 6.2% reported an 'other' referring provider which includes nurse practitioners, genetic counselors or some other practitioner not on the list.
- Among males, 14.5% reported they referred themselves to genetic counseling compared to 6.5% of females, which was statistically significant.

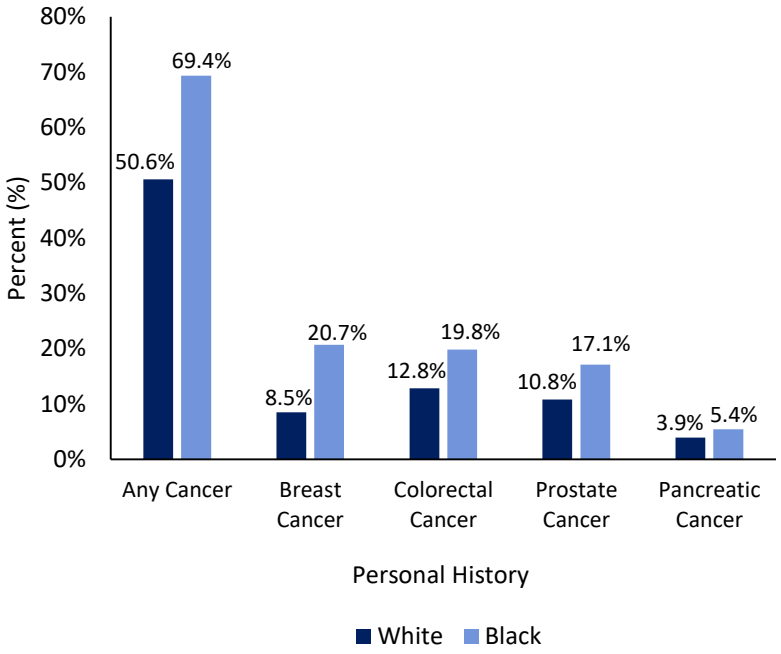
Referring Provider Type among Males in the HCN Database, 2008-2017



Personal Cancer History among Males by Race

- A total of 1,224 (51.6%) males reported having a personal history of cancer (data not shown).
- There was a statistically significant difference between races, with regards to having a personal history of cancer.
  - 69.4% of Black patients and 50.6% of White patients had a personal history of cancer.
- A total of 222 (9.4%) males reported a personal history of breast cancer (data not shown).
- A significant difference in personal history of breast cancer existed between races.
  - Among males, 20.7% of Black patients and 8.5% of White patients reported a history of breast cancer.

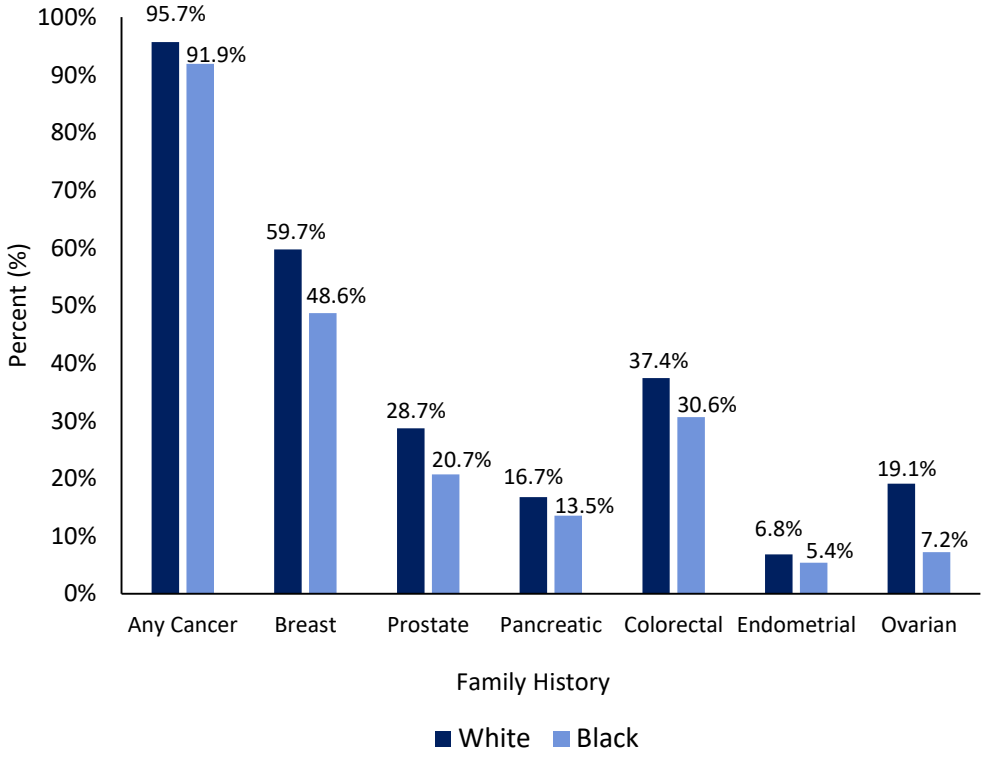
Personal Cancer History among Males in the HCN Database by Race, 2008-2017



Familial Cancer History among Males by Race

- There was no significant difference between races in reporting a family history of any type of cancer.
- There was a statistically significant difference between race and having a family history of breast cancer.
  - 48.6% of Black male patients and 59.7% of White male patients had a family history of breast cancer.
- A significant difference between family history of ovarian cancer existed between races.
  - 7.2% of Black male patients and 19.1% of White male patients reported a family history of ovarian cancer.
- There were no significant differences between races in reporting a family history of colorectal, endometrial, prostate (trending), or pancreatic cancer (data now shown).

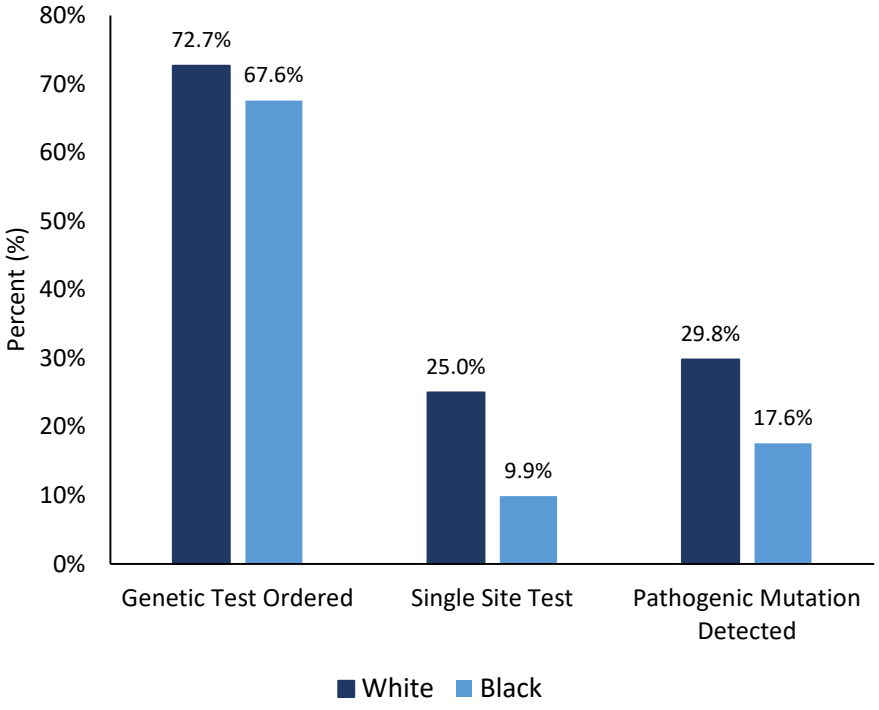
Familial Cancer History among Males in the HCN Database by Race, 2008-2017



Genetic Testing among Males by Race

- A total of 1,712 (72.1%) males had a genetic test ordered.
- The percent of White males who had a genetic test ordered compared to Black males was not significantly different.
- White males were statistically more likely to have a single site test ordered compared to Black males.
    - Among males, 9.9% of Black patients and 25.0% of White patients reported having a single site test.
- White males were statistically more likely to have a pathogenic mutation detected compared to Black males.
    - Among males who had a genetic test, 17.6% of Black patients and 29.8% of White patients had a pathogenic mutation detected.

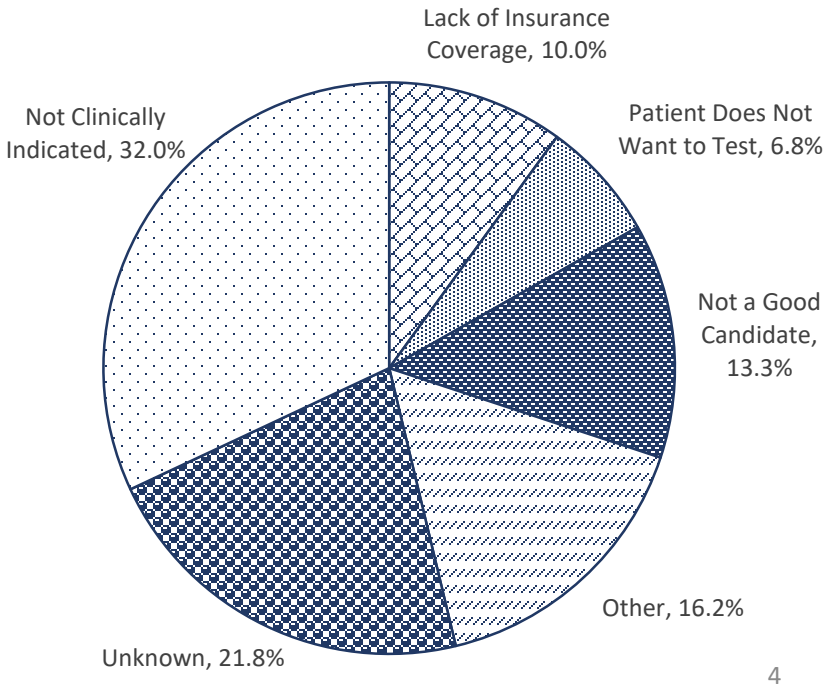
Genetic Testing and Pathogenic Mutations among Males in the HCN Database, 2008-2017



Reason why Testing was not Pursued among Males

- A total of 662 (27.9%) males did not have a genetic test ordered, of which 78.2% provided a reason for not undergoing genetic testing.
- The most common reason for not having a genetic test ordered was due to testing not being clinically indicated (32.0%).
- Lack of insurance coverage was the second most common reason for not having a genetic test (10.0%).
- Among males who did not have a genetic test, 6.8% decided they either did not want to know if they had a pathogenic mutation or they needed more time to think about having the test.

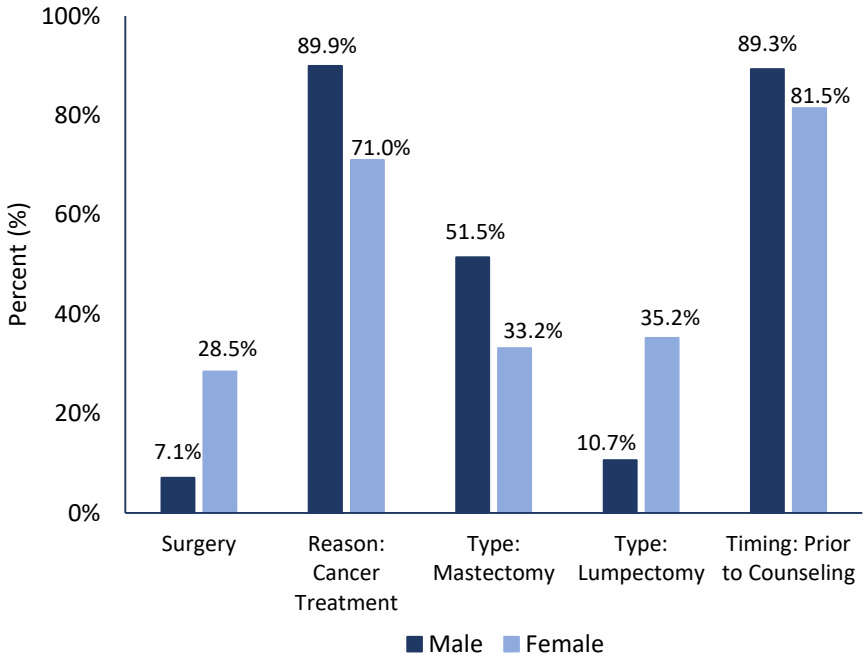
Reason Why Genetic Testing was not Pursued among Males in the HCN Database, 2008-2017



Surgical Procedures by Sex

- There was a statistically significant difference between sexes regarding reporting a surgery.
  - A total of 169 (7.1%) males and 7,689 (28.5%) females reported having a surgery related to HBOC.
- Cancer treatment was the most common reason for surgery with 89.9% of males and 71.0% of females citing cancer treatment as their reason for surgery, which was statistically significant.
- Most patients had surgery prior to counseling with 89.3% of males and 81.5% of females reporting having surgery prior to counseling, which was statistically significant.

Characteristics of Reported Surgical Procedures Related to Hereditary Breast and Ovarian Cancer Syndrome among Patients in the HCN Database by Sex, 2008-2017



Summary

Methods: Incidence and mortality data was obtained from MCSP and Vital Records while genetic counseling and testing information was analyzed using data obtained from the Hereditary Cancer Network. Significance was based on chi-square analyses with a significance value set to be $p < 0.05$.

Conclusion: In this dataset, males were more likely to seek counseling at an older age compared to females. Significant differences between sexes were also found when examining referral provider type and surgery characteristics. Although Black males were underrepresented, making up less than eight percent of the database, significant racial differences were found among men. Sixty-nine percent of Black males had a personal history of cancer compared to 50.6% of White men. White men were more likely to have a family history of cancer compared to Black men. It is important to ensure all male cancer patients are being appropriately referred to genetic counseling, so they can be aware of their mutation status and inform their families. One way to increase genetic counseling in males is by educating the public and healthcare providers about the need to know familial cancer history. If males with a strong family history receive a referral to genetic counseling earlier in their lives, proper management can begin if a pathogenic mutation is found. By identifying men with a pathogenic mutation before they develop cancer, the burden of hereditary cancer could be reduced.

For More Information:

Visit www.Michigan.gov/hereditarycancer to learn more about hereditary cancers
Visit www.Michigan.gov/cge to view more data on hereditary cancers

Suggested Citation:

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References:
1. Petrucelli N, Daly MB, Pal T. BRCA1 and BRCA2 Associated Hereditary Breast and Ovarian Cancer. Gene Reviews (2016)
2. Genetic/Familial High-Risk Assessment: Breast and Ovarian Version 1.2018. National Comprehensive Cancer Network (2017)

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